

A photograph of a car's side-view mirror. The mirror reflects a road that curves to the right, lined with trees and greenery. The sky is blue. Overlaid on the reflection is the title of the presentation in white text. At the bottom of the reflection, there is a warning in a smaller, semi-transparent font.

Reflections on Capacity Building: Evolving from a Community-Based Organization into a Research Partner

OBJECTS IN THE MIRROR ARE
CLOSER THAN THEY APPEAR

Photo by Pratheep P.S, www.pratheep.com



Janice Barlow, Executive Director
Partnership for Environmental Public Health

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Historical Perspective



Photo by Dennis Anderson

Zero Breast Cancer

Vision

To make zero breast cancer a reality for the next generation of women

Mission

To find the causes of breast cancer through community participation in the research process. We focus on identifying environmental factors and the role they play in the development of breast cancer at all stages of life and across generations

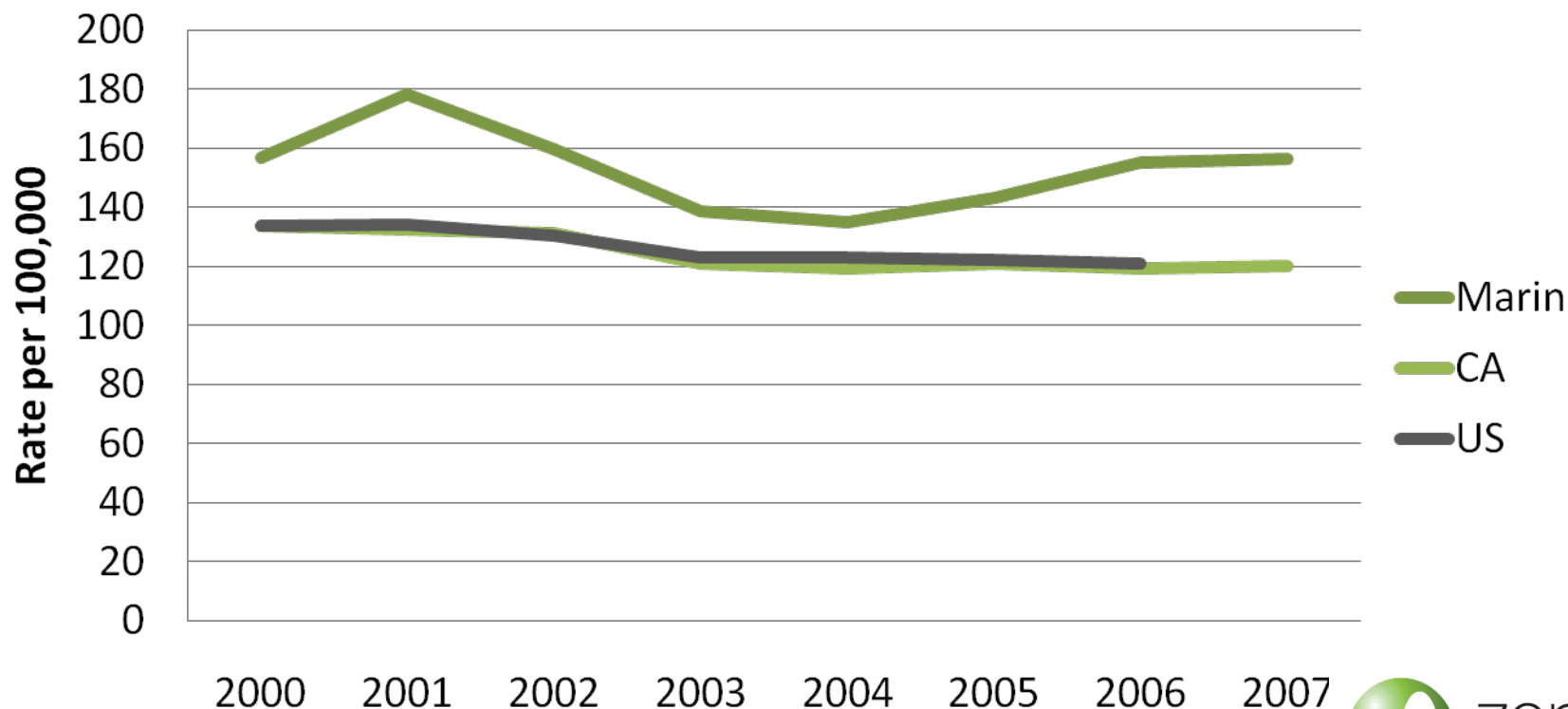
Incidence Rates: Invasive Breast Cancer

All Races/Ethnicities

2000-2007

Rates are per 100,000

Age Adjusted to the 2000 US Std. Population



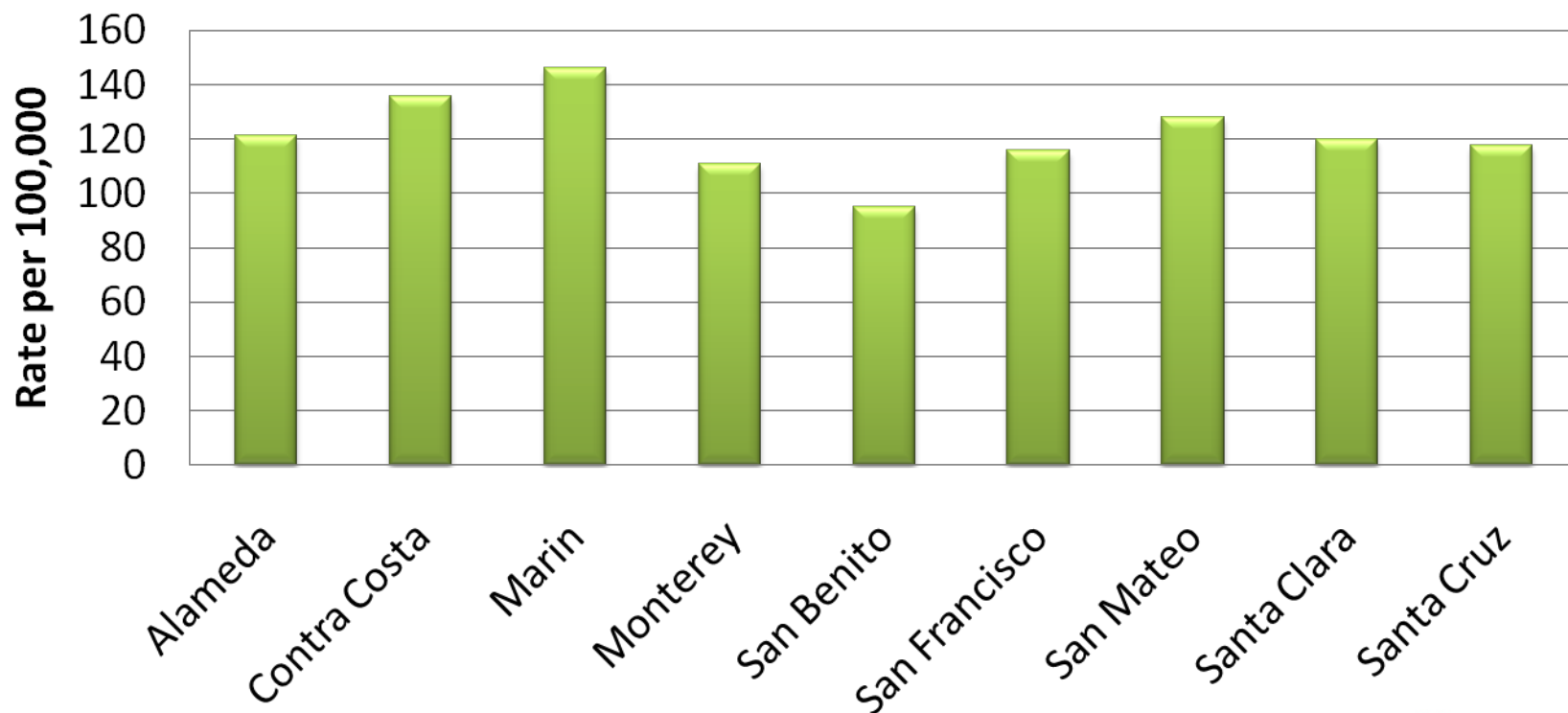
Incidence Rates: Invasive Breast Cancer

All Races/Ethnicities

Bay Area Counties 2003-2007

Rates are per 100,000

Age Adjusted to the 2000 US Std. Population



Community-Based Participatory Research

Community-based participatory research is a *“collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community, has the aim of combining knowledge with action and achieving social change to improve health outcomes and eliminate health disparities.”*

WK Kellogg Foundation Community Health Scholars Program



The Adolescent Risk Factor Study and the Development of Breast Cancer in Marin County, (1997-2002)

The Adolescent Risk Factors Study and the Development of Breast Cancer in Marin County (ARFS) was a community-based, participatory research study funded by the California Breast Cancer Research Program (1997-2001).

It was a collaboration between Zero Breast Cancer, formerly Marin Breast Cancer Watch, and University of California, San Francisco. Researchers from the Northern California Cancer Center, Lawrence Berkeley National Laboratory and Kaiser also participated in the study.

The study was designed to understand if adolescent and pre-adolescent exposures and experiences differ between women with and without breast cancer living in Marin County.

Poster Child Example of CBPR almost to the end.

Building Research and Community Capacity

Spawned additional studies and peer reviewed publications using the ARF's data:

- Recent changes in breast cancer incidence and risk factor prevalence in San Francisco Bay Area and California women: 1988-2004 (2007)
- Risk Factors for Estrogen Receptor Positive Breast Cancer (2005)
- Geographic Excess of Estrogen Receptor-Positive Breast Cancer (2003)
- Risk factors for breast cancer in a population with high incidence rates (Adolescent Risk Factor Study) (2003)

Laid the foundation for bringing in funding for and community participation in additional research:

- Personal Environmental Risk Factor Pilot
- Marin Environmental Data Study
- the Marin Women's Study
- Cancer Clustering for Residential Histories
- Bay Area Breast Cancer and the Environment Research Center
- Pathways: Prospective Study on Breast Cancer Survivorship

Translating Research into Action

Adolescent Breast Cancer Prevention, Risk Reduction and Education Project (2003-2007) is community-based education program funded by national and local breast cancer foundations.

The project is a collaboration between Zero Breast Cancer and Tamalpais Union High School District. A community advisory board informed the design, implementation and interpretation of the project's independent outcome evaluation. The project was created to:

- Communicate information learned from the *Adolescent Risk Factors Study* and related research suggesting that puberty and adolescence may be influential periods for the development of breast cancer.
- Determine whether a single-lesson breast cancer prevention, risk reduction and education module delivered through peer educators is a good model for disseminating breast cancer research findings and preventive messages to adolescent girls.

Targeted Dissemination of Research

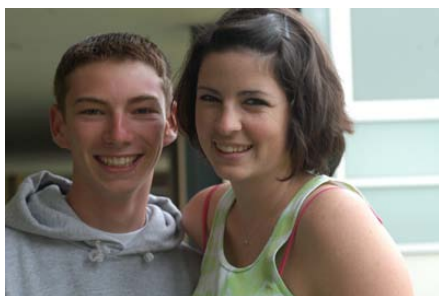
Adolescent Prevention Risk Reduction and Education Program



“I did learn the environment can have a large effect on breast cancer”

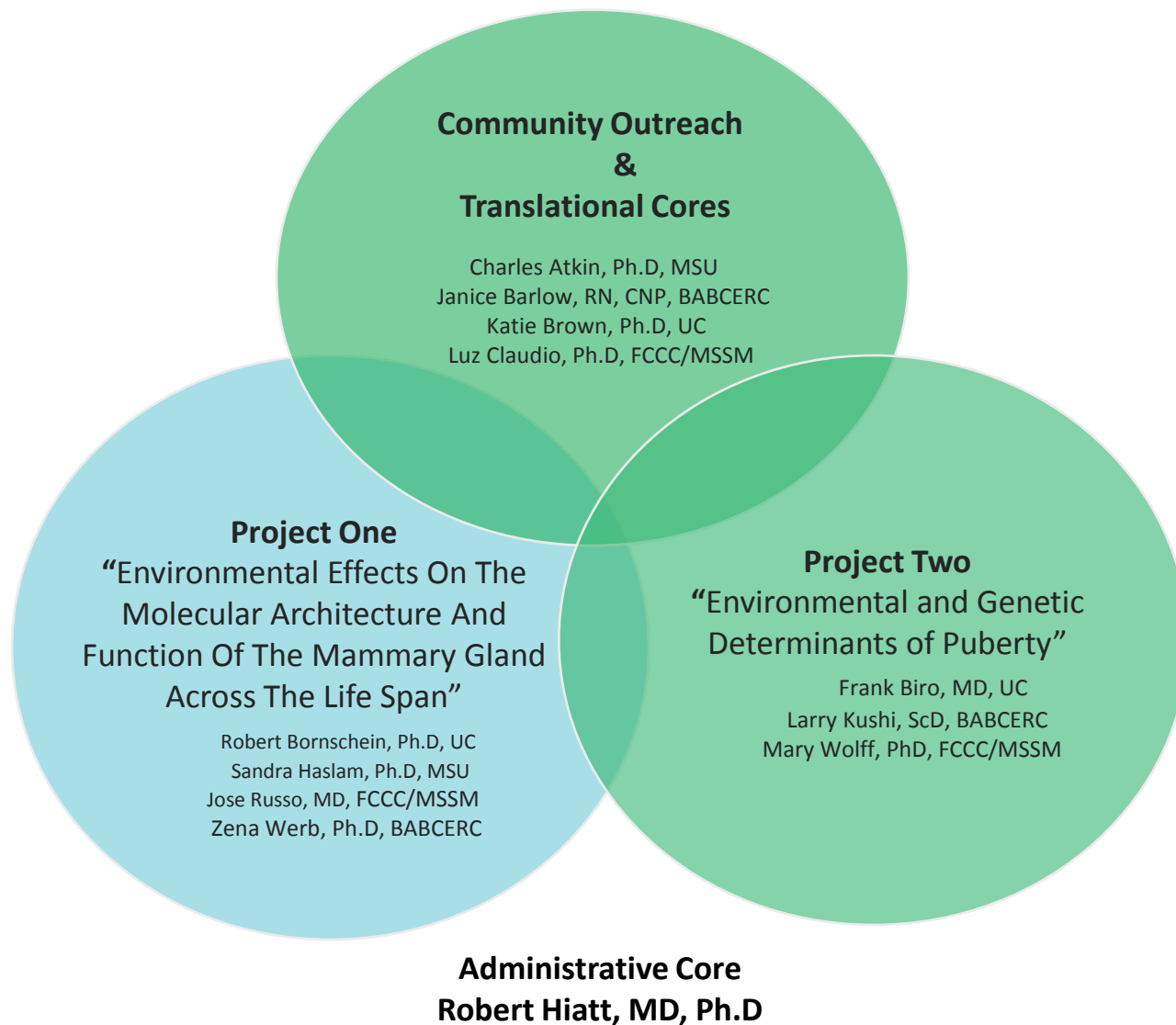


“It’s really important to convey this information on risk factors so we can make better choices, like how to take care of your body and how healthier choices can benefit you”





Bay Area Breast Cancer and the Environment Research Center



Key Success Factors

- Research topic is of concern to the community who are continually involved
- Good data is continuously available to the community for *their* use
- Trusting partnerships and collaborations with academic researchers have been built over time
- Diverse organizational funding sources

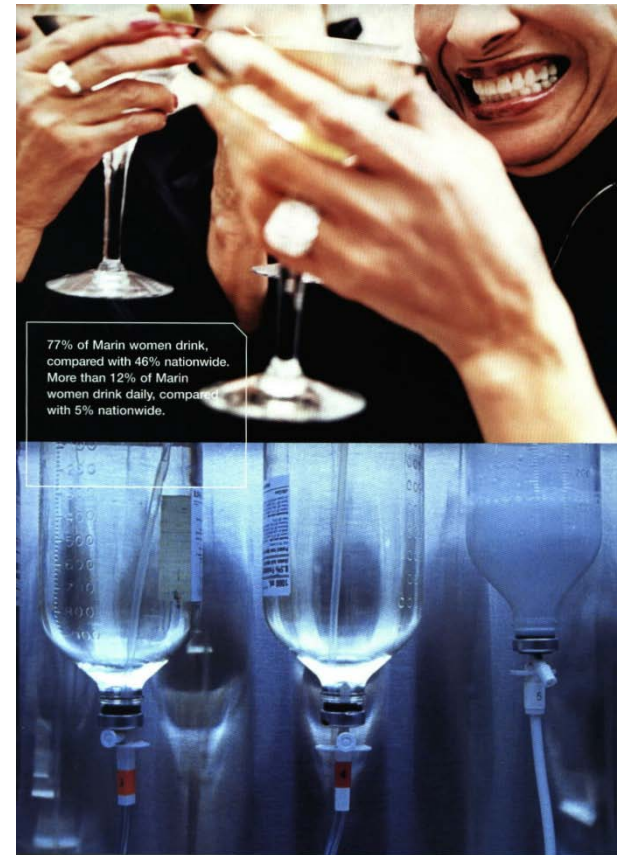
Lessons Learned

- Add value to everything you do
- Share your knowledge in peer-reviewed publications
- Anticipate the impact of the research findings on the community

Lessons Learned

Impact of the research findings on the community:

- Stigmatizing effects of identifying the community being researched
- Role of environment in breast cancer (rebuttal to comments made by media and academic partners)



Role of Environment in Breast Cancer

“The similar average ages of first residence and total years lived in Marin for cases and controls do not support (but cannot completely rule out) the hypothesis that there is some agent specific to Marin County, such as a particular water source, that might increase the risk for breast cancer.”

Breast Cancer Research 2003

“Moreover, cases and controls were similar with respect to age at first residence and to total years of residence in Marin County. This similarity fails to support exposure to a regional environmental toxicant as an explanation for the cluster.”

Breast Cancer Research 2003

“Results from ARFS indicated that outdoor pollution was unlikely to be responsible for the high breast cancer incidence in Marin.”

UCSF Comprehensive Cancer Center Report, Fall 2007

Conclusion

Zero Breast Cancer's success in evolving from a local, community-based organization to a partner in a large national multi-center research center was an outcome of the two main capacity-building approaches we have used and continue to use

- A community organizing approach
- A partnership approach



Acknowledgments

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- Community Outreach and Translation Core (COTC) members
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